



**QUEEN'S
UNIVERSITY
BELFAST**

Peer advice giving from post-treatment to newly diagnosed esophageal cancer patients

Graham-Wisener, L., & Dempster, M. (2017). Peer advice giving from post-treatment to newly diagnosed esophageal cancer patients. *Diseases of the Esophagus*, 30(10), 1-7. <https://doi.org/10.1093/dote/dox089>, <https://doi.org/10.1093/dote/dox089>

Published in:
Diseases of the Esophagus

Document Version:
Peer reviewed version

Queen's University Belfast - Research Portal:
[Link to publication record in Queen's University Belfast Research Portal](#)

General rights

Copyright for the publications made accessible via the Queen's University Belfast Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The Research Portal is Queen's institutional repository that provides access to Queen's research output. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact openaccess@qub.ac.uk.

Peer advice giving from post-treatment to newly diagnosed esophageal cancer patients

Lisa GRAHAM-WISENER^{1,2} and Martin DEMPSTER²

¹ Marie Curie Hospice Belfast, Marie Curie Cancer Care, Belfast.

² School of Psychology, Queen's University Belfast

Word Count: 5266

Contribution of authors: Conception or design of the experiment(s), or collection and analysis or interpretation of data: all authors. Drafting the manuscript or revising its intellectual content: all authors. Approval of the final version of the submitted manuscript: all authors.

Short form title: Esophageal cancer peer advice

Corresponding author: Lisa Graham-Wisener, Marie Curie Hospice Belfast. 1a Kensington Road, Belfast BT5 6NF, Northern Ireland. Email; lisa.graham@mariecurie.org.uk. Telephone; +44(0)28 90882048.

Abstract

The benefits of peer support in cancer care include the sharing of information and experience, supporting adjustment by providing an illness trajectory which cancer patients can use to prepare for their own cancer journey. Information from peers is prioritized by esophageal cancer patients, yet the content of this experiential information is not well understood. The purpose of this study was to understand the content of peer advice giving from post-treatment to newly diagnosed esophageal cancer patients. Esophageal cancer survivors (n=23) at median 67-months post-diagnosis completed a single open-ended survey item which asked for advice they would give to individuals newly diagnosed with esophageal cancer on how to cope emotionally with the cancer journey (including adjusting to life after treatment). Transcripts were assessed using qualitative content analysis, with five categories of advice identified; social support, psychological approach, realistic expectations, support from healthcare professionals and self-care. The categories of advice reported were distinct from information needs prioritized by clinicians. This study demonstrates that experiential information is accessible and has the potential to identify neglected information and supportive care needs, and may have a potential use in delivery of psychological support to newly diagnosed patients.

Keywords;

Esophageal Neoplasms; Survivors; Peer Group; Patient Preference; Patient Education

Introduction

Esophageal cancer patients encounter a demanding post-surgical recovery period with sustained impact on physical functioning [1], with the importance of a ‘shared identity’ emerging as a central theme to adjustment post-treatment [2]. Survivors emphasised the value of receiving information from individuals with lived experience of esophageal cancer, and felt this information would have been valuable during the more acute stage of their illness to provide normalisation of feelings, reassurance, non-defensive relating, hope and inspiration [2]. Esophageal cancer survivors reported information-giving by fellow patients to be of greater value than from clinicians [3].

Information from peers may provide an illness trajectory which patients can use as a guide to prepare for their own cancer journey [4]. From previous research with esophageal cancer patients [2] interaction with peers through patient support groups is reported to impact both positively and negatively on an individual’s beliefs and goal setting, in line with the Common-Sense Model [5]. Illness beliefs are reported to be relatively consistent over time [6;7] however it is likely that an individual’s expectations of their illness are more susceptible to change dependent on how they prioritise the source of the information.

Despite the outcomes from cancer patient support group attendance receiving critical attention [8], the process by which group attendance affects outcome including the role of peers in providing information is not well understood. Attempts to evidence the content of peer-advice giving in cancer have largely involved the analysis of online support forum content [9;10] with the exchange occurring through the constructed practices of an online community [11]. Experiential information itself has received little research enquiry with exception [4], with need to build an understanding of uniqueness of content. There is emerging acknowledgement of the ‘expert patient’ as central to self-management of illness for both the patient and peers [12]. Understanding the content of peer advice giving is important to inform if and how peer advice may be utilised as a form of support for newly diagnosed patients. Previous research largely focuses on advice giving in response to questions asked by other patients, and so does not reflect the information which longer term cancer patients (post-treatment), who have

been given opportunity to adjust to their illness, would prioritise themselves as being important. This would appear to be a useful area for enquiry given the discrepancy between patient and health care professional information priorities [13] with potential for patient peers to identify neglected information and supportive care needs.

The current study aims to identify the content of written peer advice from post-treatment to newly diagnosed esophageal cancer patients. Having undergone a significant period of adjustment to their illness, post-treatment esophageal cancer survivors are more likely to offer accurate and realistic advice to newly diagnosed patients, and be considered ‘experts’, more likely resulting in the successful upward social comparison reported as necessary in peer support research [14]. The objectives are to i) identify the nature of peer advice considered to be important by patients, and ii) make inferences about the potential use of peer advice in the delivery of psychological support to newly diagnosed patients.

Materials and Methods

Participants and Procedures

Post-treatment esophageal cancer survivors were identified through the supporter database of the Oesophageal Cancer Fund, an Ireland-wide charitable organisation which raises funds for research and promotes esophageal cancer awareness. Eligible esophageal cancer survivors received participant information and survey booklets sent by post. Eligibility criteria included an understanding of the English language, a diagnosis of esophageal cancer and having undergone treatment for the cancer with curative intent. The survey pack was returned to the researchers by post, with one telephone reminder if necessary.

Ethical approval for the study was gained from the University Ethics Committee.

Measures

The importance of peer advice giving was outlined to participants, “*Cancer survivors can provide a unique kind of emotional support. They can offer comfort and empathy by virtue of having gone through the experience, which can be invaluable to those individuals and their families newly diagnosed with the illness*”. Participants were then asked for any advice they would give to individuals newly diagnosed with esophageal cancer on how to cope emotionally with the cancer journey (including adjusting to life after treatment).

Other measures included in the survey pack included –

Demographic and health related items – demographic detail included age, gender, ethnicity, education, employment status, medical background (e.g. doctor, nurse), and marital status. Health related items included type of cancer, stage (if known), time of diagnosis, time of treatment end, and number of co-morbid conditions.

Analysis

The transcripts were analysed using conventional qualitative content analysis [15] where categories are identified inductively as emerging from the data. This approach was chosen as existing research literature is limited, with the single open-ended question encouraging a direct response from participants without preconceived categories.

The transcripts were analysed by the two researchers, who first independently familiarised themselves with the transcripts; then independently derived initial codes which captured key concepts using the respondent’s exact text; and then sequentially sorted codes into subcategories. This preliminary coding framework was iteratively applied to all transcripts, amended as required with new codes. Identified subcategories when compared were largely similar between the two researchers; any discordance agreed through discussion.

Results

Sample Characteristics

Of the 35 survivors invited to participate in the study, 23 returned a survey (66% return rate).

Findings

Responses varied in length from two short sentence fragments (26 words) to long passages (3 A4 pages). Five categories were identified from the advice respondents shared in their written narratives (social support, psychological approach, realistic expectations, support from health care professionals and self-care) with subcategories and an illustrative quote detailed in the coding tree (Table 2).

The number of advice categories reported by each respondent varied with a range of 1 to 6, with respondents reporting across a median of 3 advice categories.

1. Social Support

Include family members

Participants reported the importance of including family members, advising patients newly diagnosed with esophageal cancer to not “*do it alone*”. Participants emphasised the role of family members in supporting the newly diagnosed patient at various stages in the illness trajectory. At diagnosis family were identified as important for emotional support and in facilitating psychological adjustment to the disease.

Participants recommended open discussion with those close to the patient and to avoid rhetoric which serves as a barrier to this, “*Speak openly about it. Don’t whisper cancer or use euphemisms such as ‘the big C’. Its name is cancer, now face it*”. This also related to discussing the esophageal cancer diagnosis with children, “*Once diagnosed my biggest fear was what would happen to my children, how they would be affected. This worry caused much*

distress and I knew I had to do something about it or it would complicate the cancer and make recovery more difficult. So I quickly sat my nearest and dearest down at different times over a period of two weeks from diagnosis and told them everything in detail, especially the children". Participants identified not engaging with family members as leading to increased distress for the patient.

One participant cited the importance of using family and friends to engage with and process the experience of diagnosis and treatment, *"After treatment finished, the enormity of the situation hit me, during the treatment I had concentrated on getting through it and wasn't in a space to reflect"*. The participant reported later being *"able to open up to family and friends"* and *"found it enormously helpful in processing what I had been through"*.

The presence of family members during active treatment was frequently cited as beneficial, *"Always have someone with you when going for treatment"*. This extended to the family member as a useful support in helping the patient to engage effectively with the clinical team. The post-surgical impact on the esophageal cancer patient's quality of life was identified, with participants encouraging new patients to be aware of the extent of the surgery and that *"family support is very important during this time"*. New patients were advised to be open to support during the post-operative period, *"Take all the help you can get as your energy will be very low"*.

Identify Peer Support

Participants identified peer support as useful in facilitating a connection through shared experience, *"It helps to talk about it with other people that have or had cancer as they have an idea what you are going through"*. Several participants recommended newly diagnosed patients to take the initiative in approaching patient associations, *"I was totally alone, and the shock following diagnosis disables a person finding out all the information"*.

Support from other cancer patients in general was perceived as beneficial in reducing risk of isolation. A more specific role was reported to exist for post-treatment esophageal cancer patients who have *“been through the process”*. As well as aiding newly diagnosed patients to navigate the complex treatment pathway, this was seen as useful in relation to practical advice regarding symptom management, *“sharing of problems and possible changes that have been successful for others”*.

2. Psychological approach

Be positive

The importance of adopting a positive frame of mind was reported by the majority of participants. Participants believed being open in expressing negative thoughts and feelings ultimately helped to facilitate a more positive outlook, *“A positive mind is really half the battle, of course you will cry but that is good. Let it out, talk about your fears. Once they’re out you can move on and continue to fight”*. Participants recommended various positive mantras for newly diagnosed patients, *“The thought has to be I will survive this and live as fully as possible”*. There was acknowledgement that adopting a positive outlook is an effortful process, *“It is hugely difficult for a long time to adjust- but you have to keep positive, which is very tiring mentally”*.

Live in the present

Participants recommended patients newly diagnosed with esophageal cancer to *“live one day at a time”* and to focus on the present, *“don’t think about the past or future”*. New patients were advised to set short-term goals in terms of how they experience and subsequently manage their illness on a particular day, *“Get help with the way you are feeling on the day”*.

Accept your diagnosis

Participants frequently reported the importance of accepting the esophageal cancer diagnosis, and focusing on the treatment and subsequent post-surgical adjustment, *“The first thing is not to panic when you hear the word cancer (like I did). As there is so much help and treatment out there”*. This extended to fostering an awareness that cancer is not an uncommon occurrence, recommending newly patients to focus on the availability of treatment.

Participants recommended acceptance as a facilitator of increasing personal control over the cancer, *“The ‘fighting/battling cancer’ terminology didn’t sit right with me. I felt that I needed to accept the cancer as ‘mine’ before I could let it go- my body had produced it and also had the power to let it go. I decided not to be a victim and to take charge and focus on what I could do to improve the outcome of my treatment”*.

3. Realistic Expectations

Recognise this is a major life adjustment

Participants reported the enormity of the surgery, *“the surgery is huge, not many people will go through that- this makes you special!”* along with the need to acknowledge a change post-surgery and to expect that adjustments will need to be made in various aspects of the patient’s life.

“I think much preparation needs to be considered after the surgery. I was so concerned with the surgery that I was caught completely unaware as to how my life would change post-op. I am still almost 2 years after the surgery getting used to my new way of living. It can be very frustrating making so many life adjustments. There are times when I feel like I regret having the surgery although I know ultimately it has saved my life.”

Participants also provided reassurance to newly diagnosed esophageal cancer patients in stressing that the cancer need not change any of the more important aspects of the patient's life "*to any great degree*", with one participant reporting the adjustments made post-surgery had "*changed my life for the better*".

Understand it takes time to recover

There was acknowledgment of a long and arduous treatment pathway, with a lengthy recovery from surgery to a good level of functioning. Participants encouraged newly diagnosed patients to be cognisant of this in order to manage their own expectations, "*understand that it will take time but Rome wasn't built in a day*".

Participants cited the importance of allowing for time to recover from active treatment before resuming normal activities, "*Take time to get yourself up and running again. I thought at times I felt better and tried to do too much which knocked me back a lot*". The significant initial impact from surgery was stressed as temporary, with participants advising new patients "*you will take time to feel well again and it is a good feeling*".

4. Support from health care professionals

Gather information from healthcare professionals

The multidisciplinary team involved in the newly diagnosed patient's care were identified as crucial for information and support. The clinical team were reported as "*the most important next to your family and friends*". Participants advised new patients to keep in close contact with the clinical team, "*Talk to doctors about what is going to happen as it will help you to understand what is about to take place*". It was suggested that a proactive approach should

be taken to making contact with cancer support centres, and that the patient shouldn't "*be afraid to ask for help*" from primary care or specialist services.

Participants advised newly diagnosed patients to prepare prompts for medical appointments to ensure their information needs are met, "*Have some questions written down to ask your surgeon because after the initial shock you will need to know more about your cancer and treatment*". Information was viewed as enabling the patient to prepare for the next step in their treatment, "*Ask questions. What's next? Most surgeons will be glad to explain and in my case the surgeon and his specialist team were extremely helpful, making me feel at ease and positive*".

Have confidence in your clinical team

Participants frequently cited the importance of having confidence in medical science and the ongoing progression in treatment for esophageal cancer, "*changes in treatment and understanding of this form of cancer are happening all the time. Never, never, never give up hope*".

Participants advised newly diagnosed patients with esophageal cancer to foster confidence in their clinical team, "*Have confidence in your surgical team. They want the best possible outcome for you*". For several participants this included handing control to clinicians, "*put your life completely in the hands of the doctors*".

5. Self-care

Make positive lifestyle changes

Participants recommended newly diagnosed patients to focus on making lifestyle adjustments towards improving their general health, during and after active treatment. This was suggested to improve not only their physical health

but also their emotional wellbeing, *“I found a good diet helped me because if you eat well, you think well and you feel better”*.

Participants frequently cited advice on making changes to eating behaviour post-esophagectomy. This included eating smaller meals and eating more often, *“the one piece of advice I would give is to eat small but often”*. Advice also concerned the timing of meals, *“try not to eat before going to bed”*. There was an understanding that newly diagnosed patients may lose interest in eating with participants emphasising the importance of persevering, *“Eat good healthy home cooked food and eat well even if you don’t feel like it. You may have to mash or liquidise everything. Do it.”*

Engage in activities for relaxation/reflection

Participants recommended newly diagnosed patients take time to engage in activities which they find relaxing, *“listen to music to help you relax and work through the pain”*. Participants recommended newly diagnosed patients to return to their interests as soon as they are able but to *“build up slowly”*.

Reflection and spirituality were also frequently cited by participants. Several participants described how engaging in religious practices were helpful, *“I derived huge support from the prayers of others and started to pray in my own way”*.

Discussion

This study with post-treatment esophageal cancer survivors has provided valuable information on the content of peer advice giving to the newly diagnosed cancer patient. Using a single open-ended question, peer advice emerged across five main categories. Each respondent reported several categories of advice, suggesting peers to perceive psychological adjustment to esophageal cancer as a complex, multifaceted process.

The emergent categories in this sample of post-treatment esophageal cancer survivors are similar to the types of peer advice reported in a study of advice giving in the written narratives of hematologic cancer patients [4], suggesting a degree of commonality in the type of peer advice reported by cancer patients.

Engaging family support was the most frequently reported peer advice category, the detrimental impact of a lack of social support well evidenced in the cancer literature [16]. Respondents empathized with newly diagnosed patients on the difficulty of disclosing their diagnosis to family, a similar issue reported by other cancer patients [17], but an area that has received little attention to date [18]. Respondents reported general difficulties in communicating with their family and identified the need to function as a cohesive unit. Previous research indicates that signposting for family support is not prioritized by healthcare professionals [13].

In previous research with esophageal cancer patients undergoing active treatment [13], the appropriateness of their emotions was a highly prioritized information need for patients but not healthcare professionals. Respondents in the current study frequently cited adopting a positive outlook, yet detailed expression of negative feelings such as fear and anger as helping to facilitate this. This may suggest a neglected supportive care need which could be facilitated with experiential advice giving, as qualitative research has identified peers as providing normalization of feelings [2]. Patients and carers with esophageal cancer report significant levels of clinical anxiety and depression [6;7], but with few cancer patients accessing psychological support, potentially as a result of stigma around mental health [19,20], peer advice may have a role in shaping help-seeking behavior.

Establishing realistic expectations for recovery and understanding the necessary adjustments to life post-diagnosis were also frequently cited. The priority given by respondents to informing newly diagnosed patients of a realistic illness trajectory on which to map their experience is supported in other peer advice giving research [4]. This relates to fostering more realistic illness beliefs, in line with the Common-Sense Model [21], with illness beliefs previously evidenced as a key determinant of psychological adjustment in esophageal cancer [6;7]. Peer advice is potentially a persuasive and fitting medium over which to modify these ‘lay’ explanations of illness.

With significant impact on health related quality of life post-esophagectomy and particularly within the first year [1], respondents agree on the importance of advising newly diagnosed esophageal cancer patients on the likelihood of a slow recovery period while instilling hope for improvement in functioning. Mok and colleagues [22] suggested empowerment following cancer support group attendance to partly be attributed to mastery over illness relating to skills and knowledge, with the advice reported in the current study on managing burdensome late effects a particularly pertinent use of peer advice in cancer populations with an arduous post-treatment recovery.

Cancer patient support groups offer an accessible form of psychosocial support, with the findings from the current study evidencing the unique content of peer information exchange and a particular role for groups which are peer led and directed. Face-to-face peer support interventions are however limited in that they are utilised by a small number of cancer patients in relative terms [23], however this may be partly mitigated by offering one to one peer-support [24] or through use of technology [25]. Written narratives are also increasingly common and accessible [26], where written education and support materials for newly diagnosed esophageal cancer patients could potentially be co-produced with post-treatment esophageal cancer patients as key stakeholders.

There are several limitations to the current study. There is no identification of which peer advice is given more importance by each individual. Future research may ask respondents to prioritise the advice reported in order to increase the trustworthiness of frequently identified advice domains. In addition although peer advice giving has many potential benefits, it is important to be cognizant of potential negative effects. Research with prostate cancer patients reported treatment decisions to be influenced more by patient anecdotes than by population-based information [27]. A priority for exploration would be assessing the response of newly diagnosed cancer patients.

Conclusion

Experiential information within cancer populations has received a lack of critical attention, despite the increasing availability of this type of information outside the

formal healthcare setting [26]. Despite varying medical and demographic factors and the differing healthcare experiences of our sample of post-treatment esophageal cancer survivors, there is commonality in terms of the frequently cited categories of peer advice. The categories of advice reported are distinct from information needs as prioritized by clinicians [13] and recognize that information needs evolve over time [28]. With information satisfaction associated with more positive beliefs around illness [29] and improved psychological wellbeing [30], peer advice may be particularly pertinent in helping patients prepare for the next stage in their illness trajectory.

Acknowledgements

Many thanks to the Oesophageal Cancer Fund, particularly Noelle Ryan (chairperson) and to the supporters who gave their time to contributing to this research.

References

- [1] Jacobs M, Macefield RC, Elbers RG, et al. Meta-analysis shows clinically relevant and long-lasting deterioration in health-related quality of life after esophageal cancer surgery. *Quality of life research*. 2014 May 1;23(4):1097-115.
- [2] Clarke C, McCorry NK, Dempster M. The Role of Identity in Adjustment among Survivors of Oesophageal Cancer. *Journal of health psychology*. 2011;16(1):99-108.
- [3] Andreassen S, Randers I, Näslund E, Stockeld D, Mattiasson AC. Patients' experiences of living with oesophageal cancer. *Journal of clinical nursing*. 2006 Jun 1;15(6):685-95.

- [4] Symes YR, Barrington C, Austin J, Wu LM, Fisher EB, Rini C. Advice to patients undergoing stem cell transplant: Content analysis of survivor peer support narratives. *Journal of health psychology*. 2016 May 29;1359105316648672.
- [5] Leventhal H, Brissette I. The common-sense model of self-regulation of health and illness. *The self-regulation of health and illness behaviour*. Edited by: Cameron LD, Leventhal H. 2003.
- [6] Dempster M, McCorry NK, Brennan E, Donnelly M, Murray LJ, Johnston BT. Do changes in illness perceptions predict changes in psychological distress among oesophageal cancer survivors?. *Journal of health psychology*. 2011 Apr 1;16(3):500-9.
- [7] Graham L, Dempster M, McCorry NK, Donnelly M, Johnston BT. Change in psychological distress in longer-term oesophageal cancer carers: are clusters of illness perception change a useful determinant?. *Psycho-Oncology*. 2016 Jun 13;6(25):663-9.
- [8] Gottlieb BH, Wachala ED. Cancer support groups: a critical review of empirical studies. *Psycho-Oncology*. 2007 May 1;16(5):379-400.
- [9] Bosio C, Graffigna G, Scaratti G. Knowing, learning and acting in health care organizations and services: challenges and opportunities for qualitative research. *Qualitative Research in Organizations and Management: An International Journal*. 2012 Nov 16;7(3):256-74.
- [10] Sillence E, Mo PK. Communicating health decisions: an analysis of messages posted to online prostate cancer forums. *Health Expectations*. 2014 Apr 1;17(2):244-53.
- [11] Sillence E. Giving and receiving peer advice in an online breast cancer support group. *Cyberpsychology, Behavior, and Social Networking*. 2013 Jun 1;16(6):480-5.
- [12] Cordier JF. The expert patient: towards a novel definition. *The European respiratory journal*. 2014 Oct;44(4):853.
- [13] Andreassen S, Randers I, Näslund E, Stockeld D, Mattiasson AC. Information needs following a diagnosis of oesophageal cancer; self-perceived information needs of patients and family members compared with the perceptions of healthcare professionals: a pilot study. *European journal of cancer care*. 2007 May 1;16(3):277-85.

- [14] Ussher J, Kirsten L, Butow P, Sandoval M. What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social science & medicine*. 2006 May 31;62(10):2565-76.
- [15] Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qualitative health research*. 2005 Nov;15(9):1277-88.
- [16] Gonzalez-Saenz de Tejada M, Bilbao A, Baré M, et al. Association between social support, functional status and change in Health Related Quality of Life and changes in anxiety and depression in colorectal cancer patients. *Psycho-Oncology*. 2016 Jan 1.
- [17] Hilton S, Emslie C, Hunt K, Chapple A, Ziebland S. Disclosing a cancer diagnosis to friends and family: a gendered analysis of young men's and women's experiences. *Qualitative Health Research*. 2009 Jun 1;19(6):744-54.
- [18] Ewing G, Ngwenya N, Benson J, et al. Sharing news of a lung cancer diagnosis with adult family members and friends: a qualitative study to inform a supportive intervention. *Patient education and counseling*. 2016 Mar 31;99(3):378-85.
- [19] Jacobs M, Anderegg MC, Schoorlemmer A, et al. Patients with oesophageal cancer report elevated distress and problems yet do not have an explicit wish for referral prior to receiving their medical treatment plan. *Psycho-Oncology*. 2016 Jan 1.
- [20] Mosher CE, Given BA, Ostroff JS. Barriers to mental health service use among distressed family caregivers of lung cancer patients. *European journal of cancer care*. 2015 Jan 1;24(1):50-9.
- [21] Leventhal EA. self-regulation of health and. *The self-regulation of health and illness behaviour*. 2003:42.
- [22] Mok BH. Self-help group participation and empowerment in Hong Kong. *J. Soc. & Soc. Welfare*. 2004;31:153.
- [23] Plass A, Koch U. Participation of oncological outpatients in psychosocial support. *Psycho-Oncology*. 2001 Nov 1;10(6):511-20.

- [24] Macvean ML, White VM, Sanson-Fisher R. One-to-one volunteer support programs for people with cancer: a review of the literature. *Patient education and counseling*. 2008 Jan 31;70(1):10-24.
- [25] Dale J, Caramlau IO, Lindenmeyer A, Williams SM. Peer support telephone calls for improving health. *The Cochrane Library*. 2008 Oct 8.
- [26] Rini C, Lawsin C, Austin J, DuHamel K, Markarian Y, Burkhalter J, Labay L, Redd WH. Peer mentoring and survivors' stories for cancer patients: positive effects and some cautionary notes. *Journal of Clinical Oncology*. 2006 Jan 20;25(1):163-6.
- [27] Denberg TD, Melhado TV, Steiner JF. Patient treatment preferences in localized prostate carcinoma: the influence of emotion, misconception, and anecdote. *Cancer*. 2006 Aug 1;107(3):620-30.
- [28] Rutten LJ, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980–2003). *Patient education and counseling*. 2005 Jun 30;57(3):250-61.
- [29] Llewellyn CD, Horne R, McGurk M, Weinman J. Development and preliminary validation of a new measure to assess satisfaction with information among head and neck cancer patients: the satisfaction with cancer information profile (SCIP). *Head & neck*. 2006 Jun 1;28(6):540-8.
- [30] Husson O, Mols F, Van de Poll-Franse LV. The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Annals of Oncology*. 2011 Apr 1;22(4):761-72.

Table 1. Sample characteristics

Variable	Survivor sample (n=23)
Age	M=58.31 (SD=12.92)
Gender	12 (54.5%) female
Ethnicity	22 (100%) white
Education	3 (13.6%) primary education
	10 (45.5%) secondary education
	8 (36.4%) third level education
	1 (4.5%) higher degree
Employment status	8 (36.4%) retired
	9 (40.9%) employed
	2 (9.1%) unemployed
	2 (9.1%) homemaker
	1 (4.5%) unable to work
Medical background	19 (86.4%) no
	3 (13.6%) yes
Marital status	18 (81.8%) married/civil partnership/co-habiting
	2 (9.1%) separated/divorced
	1 (4.5%) widowed
	1 (4.5%) single
Cancer stage	4 (18.2%) stage 1
	2 (9.1%) stage 2

	3 (13.6%) stage 3
	13 (59.1%) unknown
Months since diagnosis	67.22 months (45.73)

Table 2. Coding tree of categories from peer advice giving

Category	Subcategory	Illustrative Quote
1. Social support	Include family members	<i>“It is a severe surgery. The support of family, friends, neighbours, work colleagues is essential”</i>
	Identify peer support	<i>“Try to talk to as many people as possible who have survived this cancer”</i>
2. Psychological approach	Be positive	<i>“After surgery you will feel rather weak but do what you can. Stay positive, for your sake and the sake of others who are supporting you”</i>
	Live in the present	<i>“Take each day as it comes, each treatment whether chemotherapy or radiotherapy is one step closer to the finishing line!!”</i>
	Accept your diagnosis	<i>“In my case I totally accepted it from the moment I was told”</i>
3. Realistic expectations	Understand it takes time to recover	<i>“You will take time to feel well again and it is a good feeling”</i>

	Recognise this is a major life adjustment	<i>“I was caught completely unaware as to how my life would change post-op. I am still almost 2 years after the surgery getting used to my new way of living. It can be very frustrating making so many life adjustments.”</i>
4. Support from HCP	Gather information from healthcare professionals	<i>“Before the operation staff at the hospital sent information, videos and literature on the operation and the environment in which the operation and recovery would take place which was very useful to me. The more knowledge I had on what was going to happen eased my worries somewhat. The most important thing to me is knowledge. Knowledge is key to my recovery”</i>
	Have confidence in your clinical team	<i>“Listen to your specialist team, trust in them”</i>
5. Self-care	Make positive lifestyle changes	<i>“The best quality fresh food you can get your hands on. Have a balance of vitamins, protein, carbs and a frequent pint of Guinness (this helped me feel normal)”</i>
	Engage in activities for relaxation/reflection	<i>“If you believe, pray. If you don’t believe start praying”</i>

Table 3. Frequency of peer advice subcategories as reported by participants (n=23)

Subcategory	No.	%
Include family members	13/23	56%
Be positive	12/23	52%
Understand it takes time to recover	7/23	30%
Gather information from healthcare professionals	7/23	30%
Have confidence in your clinical team	7/23	30%
Engage in activities for relaxation/reflection	7/23	30%
Identify peer support	6/23	26%
Make positive lifestyle changes	6/23	26%
Live in the present	5/23	22%
Accept your diagnosis	5/23	22%
Recognise this is a major life adjustment	3/23	13%